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The Disaster of Idiocy

The Predictability of Mongolism Imposes A New Burden on Our Moral Attitudes

By Joshua Lederberg

Science and Man

OF ALL the species on earth, man is in many ways the least well understood as a biological object. One of the more scandalous errors was the one generally accepted for several decades that normal human cells contain 24 pairs of chromosomes. It was just ten years ago that J. H. Tjio and A. Levan, working at Lund, Sweden, looked more perceptively through their microscope to find that the correct number was 23 pairs, or 46.

Forty six or 48; what could be a more academic hairsplitting by basic researchers? Certainly, few biologists dared to predict how quickly and dramatically the exact knowledge of the human chromosomes would illuminate a major mystery of medicine, though the chromosomes were well known to be the seat of hereditary information.

By 1959, however, a Parisian pediatrician, J. Lejeune, showed that in "Mongolian idiocy"—a misnomer, as it has nothing to do with the Mongolian peoples—the afflicted children have 47 chromosomes. The change from the expected 46 is usually an aftermath of some obscure accident in the separation of chromosome pair No. 21 while the egg matures in the ovary. This disease, now properly called 21-trisomy disease, is one of the most severe forms of mental retardation.

IT OCCURS at an over-all rate of about 1500 per million births but very much more often in births to older mothers. The risk rises over 20-fold to 3 per cent or more of the births, happily fewer in total numbers, to women 45 and over. This was noticed by a British geneticist, Lionel Penrose, over 30 years ago. Since then, no intelligent woman could avoid some rational anxiety about the outcome of a pregnancy in her later years.

It is frustrating to know this much about the disease yet have no clear picture how to forfend it and even less how to remedy it for the child. In fact, it is not so much the child who suffers, barring neglect, but the family and the community into which he is born. We simply do not know just how to deal with such parahuman beings.

By nurturing the frail 21-trisomics through the crises of birth and early infancy, medicine imposes an enormous emotional and economic burden on a luckless family. We do not even have an insurance system that could help even out this burden, especially for the first four or five years before the child might be institutionalized.

IT IS ALSO just ten years ago that several workers, in Israel, Denmark and the United States reported that studies on the cells of unborn infants made it possible to predict their sex. Obtaining these cells, by sampling the amniotic fluid, is a procedure that took some time to certify as reasonably safe. Its possible hazards are probably still too poorly known to justify it for routine sex prediction merely to satisfy parental curiosity.

However, it has gradually been shown, mainly by American and British researchers, that studies on the chromosomes of these cells could also detect 21-trisomy disease perhaps as early as the 15th week of pregnancy, a time when interruption (therapeutic abortion) is still medically feasible.

It is too soon to advocate the routine use of the amniotic fluid test except for research purposes. But it is virtually certain that it will be available within a few years and even now we cannot evade thinking about a responsible policy on the law of therapeutic abortion based on this information.

KNOWLEDGE is often uncomfortable. Most of our moral attitudes, and especially those about human reproduction, stem from a tradition that was blissfully ignorant of such embarrassments as the ability to predict a monstrous birth. In any case, the crudeness of infant care disposed of the least hardy of the anomalies. For the rest, the culture was less complex and less demanding and could find a productive role for some poorly educable near-humans.

In truth the occasional appearance of a parahuman organism might help teach us something about human nature. But our present social system exacts too painful a charge to justify burdening a mother with such an experiment, and certainly not against her informed wish. If we cannot change the system so that a trisomic birth can be a joy to its mother, how can we humanely deny a woman the use of scientific techniques of prediction and, beyond them, the remedy of interrupting a pregnancy whose culmination would be a major personal disaster?

This policy must still be construed as an expedient while we continue our research on fundamental aspects of human development. Then at an even higher level we will see the use of science to human advantage —no doubt with further perplexities of moral decision to take the place of our present ones.